DOI:
10.1007/s00134-016-4630-y

Document Version
Peer reviewed version

Dr Richard Harding (*corresponding author*)

Cicely Saunders Institute

Dept of Palliative Care, Policy & Rehabilitation

King's College London

Bessemer Road

London SE5 9RJ

+442078485518

Richard.hardiing@kcl.ac.uk

Dr Philip Hopkins

Critical Care

King's College Hospital NHS Foundation Trust

Dr Victoria Metaxa

Critical Care

King's College Hospital NHS Foundation Trust

Professor Irene J Higginson

Cicely Saunders Institute

Dept of Palliative Care, Policy & Rehabilitation

King's College London

Dear Editors

We are not using tools to optimise communication with patients and families facing uncertainty in the ICU.

Many ICU admissions involve "clinical uncertainty", i.e. treatment, prognosis or recovery are unpredictable. With 21% ICU mortality rate, rising to 80-90% after forgoing "life-sustaining" therapies[1]. staff and families face complexity decision-making and potential treatment withdrawal. Communicating uncertainty to distressed families with heterogeneous information preferences can be challenging.[2]

Challenges in ICU end-of-life care may be due to rapid changes in patients' conditions, prognostication difficulties, inadequate verification of patient/family preferences, poor information sharing, prior family understanding of condition, reluctance to plan for treatment withdrawal, lack of patient capacity, low institutional and staff ability to support spiritual beliefs and cultural values, and suboptimal team communication [3].

To determine the need for, and acceptability of, tools to address clinical uncertainty and communication needs for patients and families in ICU, we conducted a UK-wide cross-sectional survey of ICUs via the UK Critical Care Society.

Of 274 UK adult ICUs, we received 85 unique ICU responses (31% response rate). The findings are summarised in Table 1. Of those currently using any tool to identify preferences for or improve end-of-life care, these were mainly pathways for treatment withdrawal rather than communication aids.

Given high mortality rates in ICU, and the complexities of appropriate communication, interventions are urgently needed to improve outcomes for patients and families. Our survey data reveal that psychosocial workers are rare in UK ICUs (a median of 0 posts), meaning that the clinical team must take responsibility for undertaking complex discussions. In current practice, communication tools to improve end-of-life care are rare. However, an important resource is present to be able to train and support ICU staff, as the vast majority has a palliative care team onsite.
The UK ICU Guidelines require establishment of effective patients/relative communication, focus on communication interventions, communication of possible care outcomes, and provision of palliative care for those who won't recover. However, a review of the international literature concluded "*we are not at a place that we can point to the practical and scalable interventions*" to ensure ICU clinicians have basic end-of-life skills for critically ill patients[4]. Given global evidence of family stress and high mortality, the development and testing of appropriate tools is a research priority. The complexity of developing, testing and implementing these tools requires careful use of appropriate evaluation methods. Novel interventions have been developed specifically for the ICU context, focusing on structured assessment and communication training, with evidence of improved outcomes[5]. The model originated in the USA, and was refined and tested in the UK. Given the lack of models in the literature originating from other countries, it is likely that the main finding from our survey holds true in other countries (i.e. that tools to aid communication with patients and families are uncommon in practice). We urge further clinical and academic research collaboration to meet the communication and psychosocial support needs of patients, families and their clinicians facing uncertainty in the ICU. Our data suggest high feasibility of a future trial. Firstly, the vast majority of ICUs have palliative care teams on site to provide education, training and mentorship. Second, the majority would participate in an experimental evaluation of a intervention to improve communication. The relative paucity of evidence on this field could be considerably strengthened by cross-national approaches. Development and testing of an appropriate intervention could harness international multiprofessional

clinical and academic ICU expertise, with an emphasis on implementation science to ensure appropriate refinement of tools to fit varying context.

Table 1 Survey findings n=85

Variable	Results Median (range)
Beds	**16 (6-76)**
Staff:	
Doctors	**18.5 (5-60)**
Nurses	**90 (13-500)**
Social workers	**0 (0-10)**
Allied therapists	**6 (0-30)**
Health care assistants	**6 (0-30)**
Pharmacists	**1 (0-4)**
Population	
Mixed	**n=78, 92%**
Surgical	**n=1, 1%**
Cardiothoracic	**n=1, 1%**
Neurological	**n=1, 1%**
Oncological	**n=1, 1%**
Currently using tool to enhance end of life care	**n=22, 26%**
Palliative care team onsite	**n=84, 1%**
Would participate in RCT to test communication aid to address clinical uncertainty and end of life	**n=59, 69%**
A communication tool to aid end-of-life to address all ICU patients due to uncertainty	**n=44, 56%**

1. **Azoulay E, Metnitz B, Sprung CL, et al. End-of-life practices in 282 intensive care units: data from the SAPS 3 database. *Intensive Care Med.* 2009;35(4):623-630.**
2. **Higginson IJ, Rumble C, Shipman C, et al. The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making trajectories. *BMC anesthesiology.* 2016;16:11.**
3. **Papadimos TJ, Maldonado Y, Tripathi RS, Kothari DS, Rosenberg AL. An overview of end-of-life issues in the intensive care unit. *Int J Crit Illn Inj Sci.* 2011;1(2):138-146.**
4. **Curtis JR. Palliative care in critical illness: Challenges for research and practice. *Palliat Med.* 2015;29(4):291-292.**
5. **Higginson IJ, Koffman J, Hopkins P, et al. Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment and Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty. *BMC Med.* 2013;11:213.**